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ABSTRACT

This paper addresses the question of what it takes for parents of people with developmental disabilities and service workers to build and maintain productive relationships. It considers whether such a focus compromises principles of self-determination and suggests that people with strong support actually have more autonomy. Eleven suggestions for improving communication between parents and service workers are offered such as remembering differences in history between parents and service providers and expanding the individual's nework of relationships. The importance of honoring powerful emotions is stressed, noting that both parents and service workers often believe they are the weaker partners in the relationship. Other principles of relationship building include naming conflicts, naming fears, and recognizing cultural differences. The metaphor of "holding 10,000 details" is used to describe the parents' and service workers' role. These details are also shown to be a source of inequality, the root of power transactions, the source of conflicts and overprotection, and closely related to the big idea of self-determination. The paper concludes by stressing that the individual with a developmental disability must be seen as a whole person in relationship to others and in their experience of disability. (DB)

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Holding the 10,000 Details

Productive Relationships Between Parents of People with Developmental Disabilities and Service Workers

John O'Brien and Connie Lyle O'Brien

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What we did to prepare this paper

Parents and guardians, people with developmental disabilities, direct service workers, administrators, and people who are exploring the new role of service broker met with us to share their ideas and experiences in 20 discussion groups that convened in Madison, Oshkosh, and Milwaukee between April 1999 and December 2000. Most of the parents we met are legal guardians of people with developmental disabilities who range in age from their teens into their 60's, with most in their 20's and early 30's. The service brokers we met were part of their county's involvement in Wisconsin's Robert Wood Johnson sponsored Self Determination Initiative

Discussion groups each lasted about two hours and included either people with developmental disabilities, or parents, or direct service workers, or administrators, or service brokers. Most groups included about 15 people, though more than 30 people attended two of the parent discussion groups. On 17 December 1999 a large group, including a number of people involved in earlier discussion groups, met for the day to consider a summary of what we heard from the discussion groups. This lead to a second round of discussions, which were summarized in a meeting on 12 December 2000. Each meeting was recorded on wall charts, which group participants reviewed and corrected.

Limitations

This report contains our reflections on what we learned by listening to the diverse voices in each group discussion. By repeatedly reviewing and discussing our summaries of the discussion groups, and by thinking about the ways in which discussion group discussions seemed to get stuck around particular issues, we identified a set of key themes to organize the report. Because we looked for links among the different groups, our synthesis may understate or even miss points that were important in particular discussions. Participants didn't agree with one another on many issues during the discussion groups and they would not necessarily agree with the points we make here.

We summarize the way separate groups of parents and service workers discussed the topic of relationships between parents and service workers. Group discussion often amplifies feelings, and groups whose members share a common identity often amplify the sense of difference between "our" group and "the other" group. We take these amplified feelings as indicators of emotional forces often present in parent-service worker relationships, but we realize that groups that mixed parents, service workers, and people with disabilities would have produced different and equally interesting perceptions.

Discussion group participants were concerned enough about creating productive relationships to be frustrated by the difficulties they experience in doing so. This report does not include the views of disengaged parents and guardians or service workers hostile to parents or disinterested in their jobs.

A few sisters who play an important role in the lives of people with developmental disabilities and act as legal guardians participated in discussion groups. We have included sisters's contributions to the discussions but we did not explore their perspective separately from that of parents. Because the role of people's sisters and brothers grows in importance, this is an important omission.

We asked people with developmental disabilities to talk with us about their thoughts about the relationships between service workers and their parents and guardians, especially now that self-determination shapes their ideas about their futures and we have drawn on what they said in what we report. We have not discussed the critical issues arising in the relationships between people with developmental disabilities themselves and their parents and their relationships with service workers.

Thanks

We are grateful to the many people who shared the experiences and ideas we reflect on in this report. Marcie Brost and Howard Mandeville had the idea for the project and, with Lisa Mills, made logistical arrangements and joined us in listening to and thinking over what the groups discussed.

We hope that those who shared their thoughts with us will find that we have echoed at least some of what concerns them. We also hope that readers will find both familiar and different ways to think about relationships between parents and staff members.

My candidate for the most distinctive and praiseworthy human capacity is our ability to trust and cooperate with other people, and in particular to work together so as to improve the future. Under favorable conditions, our use of this capacity culminates in... projects aimed at improving our communities in such a way that our descendants will be still better able to trust and cooperate, and will be more decent people than we our selves have managed to be.

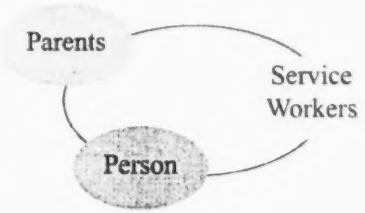
–Richard Rorty

Our question

How can differences in perspective and resources increase security and opportunity?

We want to better understand what it takes, through time, for parents of people with developmental disabilities and service workers to build and maintain productive relationships. Productive relationships creatively use differences in perspective, understanding, and resources to increase the experience of security and opportunity for people with developmental disabilities.

Most people agree on the benefits of productive relationships between parents and service workers. Such relationships can extend knowledge of a person, expand information available to a person, multiply resources available to a person, increase accountability to a person, and deepen commitment. Even when deference to legal guardianship does not require service workers to seek parental consent to a person's plans, most accounts of good practice call for at least a measure of family involvement. Even when they are not legal guardians, most parents remain concerned about a person's security and happiness.



However beneficial productive relationships may be, they are difficult to establish and easy to damage. The parents we listened to play an active role in their son's and daughter's lives and live in places noted for the quality of services for people with developmental disabilities. The service workers we listened to have long-term commitments to the work of supporting people with developmental disabilities and work for agencies with good reputations. Both parents and service workers identified more frustrations and ways that their

Richard Rorty (1999). *Philosophy and social hope*. London: Penguin Books. Page xiii

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relationships become difficult than satisfactions and things that work in their relationships.

Parents and service workers keep a sort of truce that leads to misunderstanding and resentment.

Many parents and service workers seem to keep a sort of truce, in which both try to make it through necessary interactions politely, in ways that avoid destructive conflict. This truce blocks the development of a strong enough relationship to allow exploration of different points of view and the creative resolution of conflicts.

A sense of being misunderstood and feelings of hurt, resentment, frustration, and anger can be nearby even when the surface of the parent–worker relationship looks calm. The easiest option leads parents and workers to withdraw from each other. Parents back away from active involvement and service workers agree to whatever parents say, though the agreement may be no more than words that don't outlast the time they are with parents. This kind of withdrawal robs people of the energy to resist the powerful social forces that exclude people with disabilities from everyday opportunities and satisfactions. And because concerns unexpressed go unsatisfied, withdrawal feeds resentment toward the others and even a sense of being victimized by them.

This difficulty hardly surprises. At every scale of human action from friendship and marriage to corporate performance and international diplomacy, inability to find productive ways to honor differing perspectives and satisfy different interests threatens good purposes. Those who achieve the capacity to surface and explore important differences in ways that build collaboration have worked hard at their relationships, with courage and care.

Awareness of the enormous human and economic costs of ignoring differences in points of view has generated useful approaches to engaging conflicts that can yield creative resolutions of conflicting interests and better mutual understanding. We believe that any of these approaches could help people with developmental disabilities, service workers, and parents to develop productive relationships. Though we will draw on some of these ways of dealing with dif-

ference, we will not attempt to summarize them because excellent written materials already introduce them.

We outline some expressions of difference between parents and service workers and consider some of their sources because we believe that expanding the variety of possible interpretations of difficult situations can help, especially when people often interpret differences as conflicts for which the other party is to blame. A number of discussion group members said that it helps to notice that other people have different ways of understanding the situations that they share. In addition to our own reflections, we suggest references that we think provide a variety of different ways to understand the conflicts that trouble parent-staff collaboration in the box on the right.

Each particular situation has its own integrity and its own complexity. We don't claim that our accounts of the ways parents and service workers can get stuck adequately explains any specific situation. We do think that people often stay stuck when they have just one way to look at a sticky situation and that people often attain some common ground when they have ways to notice and appreciate how very differently others may see things.

Most important, writing words about relationships counts for little compared to the hard work of intentionally cooperating with others who have different ways of being and understanding.

Four overlapping streams of work seem promising. The Harvard Negotiation Project has created a variety of training activities and books to disseminate their research on principled negotiation of conflicts. See Roger Fisher & William Ury (1981). *Getting to yes: Negotiating agreement without giving in.* Boston: Houghton Mifflin. Roger Fisher & Scott Brown (1998). *Getting together: Building a relationship that gets to yes.* New York: Viking Penguin. Douglas Stone, Bruce Patton, & Sheila Heen (1999). *Difficult conversations: How to discuss what matters most.* New York: Viking. The Society for Organizational Learning has applied the disciplines of dialogue and action science to develop shared understanding and common purpose among people with divergent and conflicting interests. See William Isaacs (1999). *Dialogue and the art of thinking together.* New York: Doubleday Currency. The Arbinger Institute has a powerful and straightforward way of explaining how people create and perpetuate problems that destroy cooperation. See The Arbinger Institute (2000). *Leadership and self-deception.* San Francisco: Berrett-Koehler. A number of human service organizations report good results from training based on the work of Steven Covey. See Steven Covey (1993). *Seven habits of highly effective people.* New York: Simon & Schuster.

Unfortunately, significant barriers hinder the application of these approaches to relationships between parents and service workers: reading is not enough, the skills involved require study and practice; most available training costs substantially more money and time than human service funders are accustomed to paying to train their own staff, much less for parent training; and, if service workers developed these skills alone, parents and people with disabilities could well experience them as just one more technique that service workers use to control them.

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Does focus on parents and service workers compromise self-determination?

The most hopeful achievements of this generation of people with developmental disabilities question the legitimacy of our topic. More and more people with developmental disabilities have exploded myths of incompetence and unacceptability by taking their rightful place as students in common schools, as productive workers and contributors to civic life, and as householders in their own right. More and more people with developmental disabilities have found their voices and organized self-advocacy groups. Their eloquence in asserting their capacities as decision makers and their skill in exposing the limitations of service arrangements that ignore or suppress their freedom inspires a new consciousness of autonomy and rights. This consciousness animates the call to reform policy and practice so that people with developmental disabilities take charge of their own lives.

Painfully aware of a history of domination justified by the assumption that disability means incapacity to decide, an assumption masked as benevolence or social necessity, this rights consciousness approaches the idea of attending to the relationship between parents and service workers with healthy suspicion. Why are we talking about other people holding the details of a developmentally disabled person's life? Why not put the person in charge of the assistance they need and be done with dependency?

Consciousness of rights shows a shadow side of cooperation between parents and staff.

Our subtitle, Productive relationships between parents of people with disabilities and service workers, properly alarms this consciousness of autonomy and rights. This consciousness sees a shadow side of parental involvement, especially in the lives of young people and adults. Parents and service workers sometimes work together in ways that control people with developmental disabilities. In the political arena, coalitions of institution workers and family members have sometimes blocked efforts to replace institutions with community services. Some parents have placed people in restrictive settings, and some parents have asserted guardianship rights to keep them

there regardless of people's own wishes and abilities. Some parents who support wider opportunities for their own sons and daughters nevertheless advocate for the principle of parental control above other values in decision making about services. Alliances between parents and staff can establish and defend service settings that unnecessarily limit people's opportunities for choice and community participation. In too many people's everyday experience, staff and parents have joined to say "no" to reasonable desires and sometimes to forbid even the simplest choices.

Why not just put people in charge of their own lives?

Why then are we talking about parents and staff? Why not put people in control of their own lives, putting staff in their proper place as the person's employees and putting the person in charge of deciding the distance they want to maintain from their parents?

Our responses cannot ever satisfy this rising consciousness of people's autonomy and rights. And we think it is good that we cannot fully answer the questions this consciousness poses, because we share much of it's reading of history and it's sense of what is possible and right. Welcoming the discomfort of questioning by this consciousness, we persist for two reasons: 1) Many people with developmental disabilities do count on other people, often including their parents, for help in making decisions; and, 2) People with developmental disabilities have more autonomy when their family actively supports them to exercise their rights.

Without help, many people can't be in charge

Inabilities in managing the details of everyday life do exist and create dependencies. The idea that people with developmental disabilities should be their assistants' boss provides a helpful corrective to unquestioned habits that turn situations of dependency into situations of domination by those who supply necessary assistance. But for many (but by no means all) people with developmental disabilities the analogy to being the boss encounters at least five qualifying circumstances.

- Inability blocks the option of exit for many people with developmental disabilities. A typical boss who loses the services of an

employee may suffer reduced efficiency, and might even go out of business, but a typical boss does not place her survival in the hands of her employees. She can walk away. Some people with severe disabilities cannot survive without assistance and many people with developmental disabilities cannot succeed at everyday tasks without consistent help. The costs of refusing assistance, or doing without it for very long, are steep.

- Difficulties in communication rooted in impairment shape the ways in which some people with developmental disabilities can express preferences and directions. Most people can identify communication deficiencies in their bosses that contribute to misunderstandings and inefficiencies, but these are usually the failings of a person who can independently originate and respond to communication. Some people with developmental disabilities can be silenced by such simple means as failing to discover or use augmented communication strategies. These people depend on their employees for the very means to give them directions.
- Some people with developmental disabilities have cognitive disabilities that shape the assistance that they require. For some people with developmental disabilities, it is limitations in literacy that make some situations unmanageable without help; making decisions and providing instructions poses little challenge. But for some others thinking seems situated firmly in concrete circumstances and choices will be clearest to those able to read the person based on having attentively shared a history of experiences.
- Scarcity of service dollars, and sometimes mutual choice, leads some parents to provide substantial assistance to their adult children. Until sufficient funding allows every person and parent a real choice, a significant number of people rely on others with whom they have a family relationship far too complex to be understood simply in terms of boss and subordinate.
- A significant number of people have legal guardians. While guardianship need not, in itself, limit a person's autonomy, it does substitute another person's decisions for at least some of a person's

judgements. In practice, this usually means that people depend on how seriously and imaginatively guardians take their duty to base choices on their best understanding of the person's distinct identity and interests.

The breadth of different abilities encompassed by developmental disability aggravates thinking about autonomy and rights. All people are equal in dignity, but people differ considerably in the amount of assistance they require to exercise autonomy. All people can think and create meaning from their experiences and problem solve, but people differ considerably in the extent to which others must attend, assist, and interpret. Some people communicate their interests with clarity and power, whether they use words or other symbols. Others have considerably more difficulty in expressing themselves. Patterning our understanding on the experience of those people with developmental disabilities who most obviously demonstrate their ability to communicate and choose would be misleading. So would a pattern based on the experience of those who rely most on others' assistance.

Sometimes people talk past one another because one person's mental map of developmental disability omits the aspect of human variety the other person has in mind. Awareness of the terrible effects of labels, especially labels that identify severe or profound impairments, makes conversation even more difficult when those who draw attention to the significant impairments some people experience get dismissed as backward or prejudiced. No doubt that negative self-fulfilling prophecies disrespect and stunt the development of people with developmental disabilities. No doubt that even those who love a person most can fall into underestimating the person's capacities. But there is also no doubt that making autonomy real for a person with significant impairments requires direct and thoughtful engagement with the practical limitations a person experiences.

People with strong support have more autonomy

The paradox that people with developmental disabilities can best express their identity and competencies when others thoughtfully recognize and respond to both their gifts and their inabilities goes deeper yet. People with developmental disabilities have more capacity to resist the forces that deny their dignity and abridge their rights when they can depend on people who know them deeply for commitment to their human dignity and support and encouragement in contributing to community life. In this, people with developmental disabilities are no different than most anybody else.

Many people find meaning, strength, and resilience in their relationships with their parents and other family members. Many people find renewed strength for their wings when –despite conflicts– they feel secure in their roots. Many people inhibit their own dreams in ways they only discover when they feel the energy that flows when family members bless those dreams. Even people cut off from contact with their families can feel deep hunger for family knowledge of them and family encouragement of their lives.*

Of course, romanticizing the contribution of families makes little sense. It might even encourage the mean spirited politics of cutting public responsibility for funding the assistance people with developmental disabilities need. Poverty, isolation, and the lack of sufficient assistance can exhaust parental ability to do the work of caring well.

Some people experience fraught and conflict ridden connections with their families. Some people feel neither kindly seen nor warmly encouraged by their parents. Some people suffer abuse at the hands of family members. In part, the struggle of those wounded in their family involves constructing relationships outside the family orbit worthy of trust as a foundation for healing and development. And sometimes this foundation supports reconciliation with family members.

Few people try to make do exclusively with the encouragement and support of family members. Most people extend their social world to include friendships and memberships. But it is exactly this joining a

* In two books for young adults, automobile assembly worker turned award-winning writer Christopher Paul Curtis embodies these realities in the stories of two 10 year old African-American boys. See (1995) *The Watsons go to Birmingham –1963*. New York: Yearling Newberry, and (1999) *Bud, Not Buddy*. New York: Delacorte Press.

reliable and supportive web of relationships beyond the family that proves very difficult for some people with developmental disabilities. Well intentioned but poorly considered efforts to emancipate people with developmental disabilities from their families risks extracting people into isolation, especially when staff with limited commitment to a person mindlessly make the separation happen through routines that leave parents feeling awkwardly unwelcome in their son's and daughter's lives.

Some parents we listened to think that staff may encourage separating people from their families as an expression of personal conflicts with staff members's own families of origin. This may sometimes explain things, but we think that unquestioned models of "normal" development more frequently encourage what one parent called "staff attempts to perform parent-ectomy" by discouraging parental relationships.

Many common accounts of normal development make separation from family of origin a necessary and critical sign of maturity. From this point of view, people who think and act primarily as individuals separated from relationships are more highly developed emotionally, cognitively, and even morally than people who think and act primarily in terms of relationships. Under this model of humanity, autonomy means doing it alone, served only when necessary by inferiors under firm control. This individualistic understanding reflects and reinforces powerful cultural forces that feed irrational fears of vulnerability, forces that also contribute to prejudice against people with disabilities. So strong is this model of normalcy as isolation that it renders the work of tending relationships almost invisible, assigning this work to people whose status and power is compromised by their acceptance of it. Since the dominant culture in North America assigns most relationship work to women, women's increasing visibility in public life has begun to raise important questions about theories of development that devalue connections.

Acknowledging the challenge of rights consciousness, we continue to explore relationships between parents and staff.

For correctives to these common ideas of development from inside the field of psychology, see Carol Gilligan (1982). *In a different voice.* Cambridge, MA: Harvard University Press; Jean Baker Miller & Irene Pierce Stiver (1997) *The healing connection.* Boston: Beacon Press; and Joyce Fletcher (1999). *Disappearing acts: Gender, power, and relational practice at work.* Cambridge, MA: The MIT Press. For a perspective on mothers of children with developmental disabilities, see Rannveig Traustadottir (1995). A mother's work is never done: Constructing a 'normal' family life. In Steven Taylor, Robert Bogdan, & Zana Marie Lutfiyya, eds. *The variety of community experience: Qualitative studies of family & community life.* Baltimore, MD: Paul Brookes Publishing., pp. 47-65. For a story of the ways these contrasting understandings work out in one person's life, see John O'Brien and Connie Lyle O'Brien (2000) *Walking toward freedom: One family's journey into self-determination.* Syracuse, NT: The Center on Human Policy (download from soeweb.syr.edu/thechp)

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Everyone agreed: poor communication is the problem and better communication is the answer.

Communication: A not so simple answer

As they considered the complex problems of relationship between parents and service workers, every discussion group adopted a common name for both diagnosis and prescription: poor communication is the problem and better communication is the answer.

Discussion group members considered how to move through the difficulties that too often keep parents and service workers from communicating effectively. They identified eleven things that anyone could do to improve even the most troubled and stuck relationship between parent and service worker.

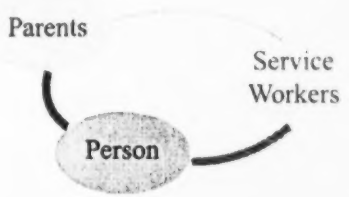
- Find time to acknowledge the difficulty and explore the other person's side. Make respectful efforts to understand the other's position before seeking to be understood by that person.
- Remember differences in history. Many people with disabilities and their parents have experienced disappointments from staff and some have experienced neglect or abuse. Staff may have come and gone, requiring people and their parents to tell and re-tell their story, orient and re-orient new people, build and re-build relationships with strangers they must entrust with their security.
- Recognize that who a person is with makes a big difference to what a person does and says. So do the demands of a person's setting and the expectations and assistance a person has experienced. It makes more sense to find out what helpful next steps might come from differences in a person's performance or statements than to have arguments of the "He can't do that!" – "Yes he can too!" or "She can't have said that!"– "Yes she did!" variety.
- Explicitly decide on ways to set and reset zones of privacy. Some things are simply a person's own business and the person should decide whether to let staff or family in on them. Some family matters are rightfully private. Some things are between the person and the staff who assist. Some things must be shared, even if it is unusual or uncomfortable to do so.
- Be clear about the responsibilities and the limitations of guardianship. Guardianship includes the obligation to make informed

For a fine discussion of privacy and communication around what many of us find a difficult subject see Karen Melberg Schwier and Dave Hingsburger (2000). *Sexuality: Your son's and daughters with intellectual disabilities.* Baltimore, MD: Paul Brookes Publishers. The book itself is a product of parent-staff collaboration.

judgements that take account of a person's unique interests and preferences. Courts limit many guardianships to specific decisions. Clarity about each guardian's authority and responsibility can reduce confusion and resentment.

- Make common cause to deal with the threats posed by cost cutting, persistent waiting lists, ineffective over-regulation, and problems in recruiting and retaining capable staff caused by poor compensation and devaluation of the work. Find ways to look beyond immediate circumstances and work to make better paid assistance available to everyone who needs it, especially people and families most at risk of being excluded because of isolation, poverty, or cultural difference.
- Invest in people with developmental disabilities, parents, and staff learning skills that will improve listening and creative negotiation of conflicts. Risk trying new ways to listen and negotiate.
- Recognize that better communication will often reveal more problems, especially at first, as people sort through important things they have left unsaid. Figure out how to make safe spaces for people to speak more honestly and listen more deeply. This will take time.
- Take responsibility for strengthening one's own relationship with the person with a developmental disability. Though it may seem odd to speak of parents strengthening their relationship with their son or daughter, a number of participants in parent discussion groups spoke of discovering new possibilities and new ways to recognize their sons and daughters as adult citizens, capacities hidden beneath old habits and assumptions.
- Either honor the other's markers of respect and trustworthiness simply because it matters to the other person or openly negotiate disagreements over them. Find ways to express honest appreciation for what the other does that contributes to the quality of a person's life.

A number of parent advocacy organizations in the US and Canada now strongly advocate less restrictive alternatives to legal guardianship. For examples see D. Hoyle & K. Harris (2000). Re-thinking guardianship. *TASH Newsletter, 26*, 11. and Ontario Association for Community Living (1998) *Position on supported decision making*. www.acl.on.ca/policy/decision.html
For discussions of guardianship in the context of self-determination, see T. Nerney & C. Mosley, Eds. (2001). *Perspectives on guardianship: implications for self-determination*. Durham, NH: Institute on Disability.



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- Though it may seem counter-intuitive, one way to diminish relationship problems is to expand the network of relationships. Encourage the person's life with friends and others. Support the person's interest in self-advocacy. See to your own personal support system. As one mother put it, "I've come to appreciate the advice you get when the airplane takes off. 'If the oxygen masks drop, put on your own mask before trying to help someone else with theirs.'"

Barriers stand in the way of following these suggestions. Simply fitting time for thoughtful conversation into overloaded schedules challenges the pace of many people's lives. Even when time can be found, productive discussion is difficult. In what follows, we will explore four challenges to better communication:

- Honoring powerful emotions
- Balancing holding the details with big ideas
- Seeing the whole person
- Deciding how much to invest in relationships

Honoring powerful emotions

Parents and service workers often feel threatened, each by the other.

Most interactions between parents and service workers happen in a cordial and businesslike way. But strong emotions often flow, mostly unspoken. In discussion groups, these emotions quickly found words that signal a situation in which both parents and service workers easily feel threatened, each by the other.

We are weak. They are strong.

Parents feel less powerful than service workers and service workers feel less powerful than parents. The challenge of better communication includes finding ways to move past the emotional deadlock engendered by this sense of threat.

These four symmetrical expressions of powerlessness outline the deadlock, and highlight important features of the circumstances that affect parents's and staff's lives and the lives of the people they care about.

1. Their shared situation tempts both parents and staff to feel disadvantaged by the others.

*Parents say** that service workers withhold information, cloak simple matters in a confusion of jargon and acronyms, confound straightforward efforts to deal with problems with a welter of defensive postures and procedures, refuse to listen, devalue their place in the lives of people with disabilities, and would (threaten to) kick the person out of their service in order to stay in control.

*Service workers say** that parents discount the importance of their commitment to people with disabilities, harbor unresolved emotional issues that distort their understanding of people with developmental disabilities, refuse to listen, and expect service workers to obey them without question.

2. Their shared situation tempts each group to feel that it makes extra effort to placate the other.

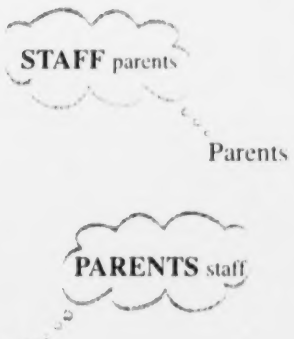
Parents say that they hold back much of what they think in deference to service workers and go out of their way to express their appreciation.

Service workers say that they handle parents with kid gloves and often comply with parental demands that make little sense or even demands that seem to them to be detrimental to the person with a disability.

3. Their shared situation tempts each group to feel that it has a claim to authority based on superior knowledge, but each holds that claim ambivalently, qualifying it with a statement about how they are "supposed to" feel.

Parents say, "We know the person best because of the longevity and depth of our bond **but** we know that we are supposed to 'let go'."

Service workers say, "We know the person best because we don't have the emotional entanglements of unresolved grief and guilt that parents do and because we have to deal with people's difficulties and dreams every day in the real world of the service system,



We are weak. They are strong.

We bend over backwards to please them.

We know best even though we aren't supposed to say so.

* This is shorthand. We don't presume to speak for all of the parents or all of the service workers that came to our discussions. We identify themes that seemed to us to come up repeatedly in different discussions. Thinking about these themes can provide some possible ways to understand a specific situation but they don't predict any particular person's experiences.

but we know that we are supposed to defer to parents because we are only in a person's life for a little while and the parents are always there."

They have to change if things are going to get better.

4. Their shared situation tempts each group to feel that the power to improve communication and better relationships lies primarily with the other side. This assignment of power increases the sense of threat and opens the way to increased fear, resentment, and blaming.

Parents say…

"If only staff would listen to us…"

"If only staff would tell us what is going on clearly and when we need to know…"

"If only staff would respect our importance and contributions…"

Service workers say…

"If only parents would listen to us…"

"If only parents would tell us what is going on clearly and when we need to know…"

"If only parents would respect our importance and contribution…"

Conflicts develop about what is proper or healthy.

Naming conflicts

Asked to name the sites of conflict between them, both parents and service workers make a similar list. Conflicts develop around differing judgements about what is proper or healthy for people with developmental disabilities in…

…use of personal money

…sexual expression

…weight and food

…religious observance

…privacy for the person or for live-in staff

…association with others

…personal appearance

…standard of housekeeping

…maintenance of house and yard

...compliance with medical regimen, especially timing and dosage of medications

...use of tobacco or alcohol or other drugs by the person or the staff

...the authority of guardians

...keeping a person's secrets.

Thankfully, no one reported chronic conflicts in all of these areas around a single person. However, parents frequently pay particular attention to one or a few of these life areas as markers of service quality or tests of staff suitability. They often recognize that their choice of markers can seem arbitrary or fussy. A number of parents would agree with the father who said, "I know it may seem a little silly to obsess about whether the lawn gets mowed, but it does matter to me that my son's house is a credit to his neighborhood. And if staff don't follow through on their agreements about the lawn, how can I trust them about more important things?"

Parents sometimes select a single marker of trustworthiness.

When conflicts in these highly charged everyday matters go unresolved for long periods of time, and especially when they go unspoken except in occasional blow-ups, people's ways of making sense of the situation make conflicts worse. Parents may explain the situation to themselves as an attempt by service workers to shift a person away from what their family values and turn them into strangers. Service workers may explain the situation as an attempt by parents to hang on too tight and stunt expression of individual rights. Each thinks that the other has a poor understanding of the implications of disability for the person.

People's ways of making sense of a situation can make conflicts worse.

Naming fears

Asked to name their fear in conflicts with service workers, parents say that they fear that service workers will hurt people with developmental disabilities or reject them and return them to their families. They feel that service workers are quick to judge them as bad parents. In the discussion groups, parents voiced fears that...

Both service workers and parents fear being hurt, rejected, and harshly judged.

...funding cuts will put service providers out of business and parents will have no alternative but to take complete responsibility for assistance or see their children homeless and on the streets

...service providers leave staff unsupervised and do not discipline staff who neglect or abuse the people for fear of penalties for violating employee rights

...service providers will impose staff with criminal histories, including theft, assault, and pedophilia, on people with developmental disabilities because of staff shortages and a misplaced concern to give people employment regardless of their history

...service providers will refuse to serve a person if the person's family uses the system's complaints procedure

...staff will steal money, possessions, medications, household items, and food

...staff will leave people unsupervised or lock people out of their homes

Remember that most parents who participated in discussion groups, and most of the people who voiced these fears, expressed overall satisfaction with the services their sons and daughters receive.

Asked to name their fear in conflicts with parents, service workers say that they fear that parents will get them in trouble in ways that could cost them their jobs, expose their service organizations to liability claims, and shame them as incompetent or immoral. They feel that parents are quick to judge them as uncaring and untrustworthy.

A shared reality

When parents and service workers stand in each other's shoes they notice what they have in common.

Taken together, these temptations define the challenges and some of the resources necessary for better communication. When parents and service workers stand for a moment in each other's shoes they notice that...

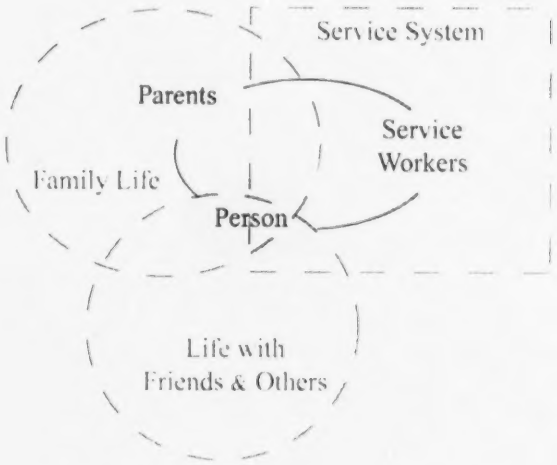
...they share a situation that engages very strong emotions and each could take responsibility for learning to function better when feelings run high

...in the other's eyes, each has the power to frustrate and threaten the other and each could make a thoughtful effort to identify and change behaviors that the other experiences as frustrating or threatening

...each has resources and knowledge that the other lacks and needs and each could look for ways to turn aside from situations of competition over which resources or knowledge confers superior status

...each has the capacity to positively influence the relationship by taking responsibility for speaking more clearly and courageously, for sincerely inquiring to understand the other's position, and for negotiating and living up to agreements that will increase trust

Parents and service workers relate at the overlap of different kinds of social systems. In an important sense service workers play a role in family life and parents have assigned roles in the service system. Service policies powerfully affect family life. Family culture and customs influence the relationship between service workers and the people they assist. A person's life with friends and others influences both relationships with family and with service workers and from time to time a person might find ways to generate conflicts between parents and service workers. With such a variety of overlaps and potential entanglements, no wonder relationships sometimes encounter confusion and misunderstanding. No wonder people sometimes decide that withdrawing from active connection offers the best chance of avoiding overload. Appreciating this complexity helps people react to relationship difficulties with compassion for themselves and the other people involved.



When parents and service workers stop to look at their environment they notice that they share a difficult civic situation that calls for their

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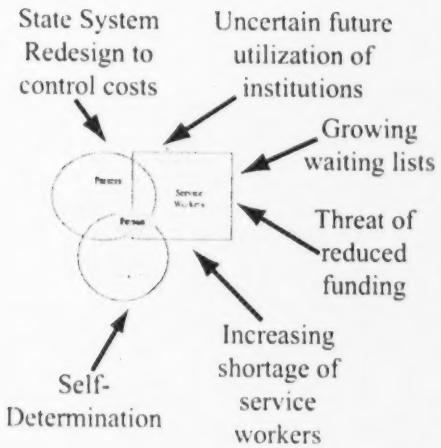
State System Redesign to control costs
Uncertain future utilization of institutions
Growing waiting lists
Threat of reduced funding
Increasing shortage of service workers
Self-Determination

best efforts in collaboration with people with developmental disabilities: a government that allows denials of needed services, waiting lists and non-competitive staff wages; a funding and regulatory structure that limits flexibility and imposes high costs of compliance; and a society that devalues people with disabilities and disrespects their rights. Each can look for ways to engage the other in resisting the negative effects of these serious problems on their own relationships and in working for change. Each can recognize that blaming the other multiplies powerlessness to the advantage of the forces that promote scarcity and exclusion and to the detriment of the people they care about.

Cultural differences can be hard to discuss

Parents and staff often differ in ways that make communication hard. Some of these differences are easier to acknowledge and discuss than others. Most people seem reasonably safe in talking about age and generational differences. It seems harder for many people to confront differences in race, ethnicity, language, religion, and income when these differences seem to them to be relevant to solving a problem. These differences grow more frequent as both the service system's workforce and its client group grow more diverse. Most people want to avoid giving offense, expressing prejudice or stereotyped beliefs, or violating others' right to be free of discrimination. This can make it feel awkward to bring up some topics.

Many people lack practice at openly discussing the meaning of cultural differences when a problem arises. As more and more people with developmental disabilities rely on staff who seem different from them and from their parents, opportunities grow for building relationships strong enough to allow people to increase their awareness and appreciation of the real diversity of their communities. But such understanding will usually come at the price of discovering respectful and honest ways to overcome anxiety and defensiveness about race, ethnicity and class, at least in the particular situation that staff and parents share with a person with a developmental disability who counts on all of them.

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Holding the 10,000 details

A mother who organizes and directs her son's personal support system provided the image that defines developmental disability in terms of 10,000 details that must be thoughtfully and competently managed in order to assure that a person has a good life. The particulars of assistance determine health and well-being, support development, shape daily routines, and define opportunities. Details range from the specifics of positioning to schedules for personal assistants to the paper work necessary to appeal an adverse bureaucratic decision. Individual characteristics and preferences specify the details that have the most immediate effect on security and development and thus on the expression of personal identity: here is the safest way to assist her to transfer; this is what soothes him when he is frightened; that is what helps him re-establish self-control; these are the subtle signals of her interest in meeting someone.

Holding the details means embodying caring attention and judgement around matters that a person can't handle without help.

Holding the details means performing tasks, but, more than that, it means embodying caring attention and judgement around matters that the person can't handle without help in performing tasks, processing necessary information, or problem solving. Interaction around the details of daily life offers opportunities for developing a relationship that provides a sense of security and discloses more of a person's individuality. It offers a privileged position for getting to know a person and noticing changes that may signal difficulties or gains that call for action. Representing a person to people or systems that have trouble recognizing the person's dignity and rights can expose the detail holder to harsh lessons about the status of people stigmatized by prejudice or depersonalized by clienthood. In its possibilities for shared satisfaction and shared difficulties, holding the details is best understood as existing between people, in relationship.

Some assistants* decline these satisfactions. They perform tasks without attention, avoid engagement with the person they help, and remain passive in the face of opportunities to represent the person. Exhaustion and isolation can account for such rote performance. So

*We use the word assistant to identify anyone who holds details that make an important difference to a person's security and well being when a person is unable to handle these details alone. A direct service worker is clearly an assistant. A person who coordinates or oversees helpers for a person is an assistant in providing supervision on the person's behalf. A parent who provides physical care or provides an adult with a place to live or supervises staff or deals with paperwork is also an assistant from this point of view.

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can pre-occupation with self or anxiety about becoming involved in another person's life.

The details are a source of inequality

The 10,000 details put a kind of inequality at the heart of this relationship: the person depends on others long-term for day-to-day assistance that he or she cannot do without. How each understands and deals with this inequality shapes the quality of both lives. This inequality can become almost irrelevant in a relationship that encompasses but moves on into shared life beyond the person's need for help with life's details. Sadly, this inequality can also result in a relationship which allows assistants to dominate a person's life for their own purposes, whether those purposes be to make a person over into the assistant's idea of "normal", or to minimize the amount of work the assistant has to do, or to defend the assistant against anxiety, or to feed the assistant's need for control, or to cover the assistant's exploitation of a person. Such is the nature of the inequality that it can protect assistants from ever having to think about their work in any but the most flattering terms of benevolence. Culture makes it easy to understand domination of people with severe disabilities as benevolence or compliance with higher authority: control happens "for the person's own good" or because a system's rules require it.

Inequality can protect assistants from ever having to think of their work as anything but benevolent.

To organize day-to-day routines, people often make a to-do list check off details as they are resolved. In life with people with substantial disabilities, details depend on each other in intricate patterns. Details that have been marked "done" can unexpectedly reappear. The prospect of more hours of paid employment scrambles daily schedules all around a person, even if an increase in earned income would be welcome and would not threaten necessary benefits. A roommate who makes an essential contribution to a household budget decides to move out. Family circumstances change and a trusted housemate moves out, creating both a sense of loss and a big hole in what had been a solid personal assistance schedule, a big hole that pulls attention away from important but less immediate details.

From this perspective, developmental disability means relying on others to hold most of these details with or for oneself because one cannot hold them alone. The more exacting the details, the more complex the disability. The more details others holds for you, the more you rely on their energy, skill, and good will. The more different people who hold the details of your life, the more vulnerable you are to their willingness and ability to deal effectively with the conflicts that will arise between them.

The more other people hold the details of your life, the more vulnerable you are.

Power is in the details

People transact power in negotiations around details. Needing long term assistance with everyday tasks opens a person to their assistant's disposition. Determining which details a person can hold for self, which details a person needs assistance to hold, and which details need holding on the person's behalf matters considerably. Holding details for a person that a person can hold for himself inhibits development. Neglecting to attend to details that are beyond the person's notice or ability compromises safety, satisfaction, and opportunity.

Power-over

For some assistants, a person's need for help creates the occasion to transact power-over them. A cruel assistant thoughtfully uses power over a person to inflict hurt and humiliation. A mindless assistant thoughtlessly enacts power-over a person in ways that impose discomfort or disregard a person's expressions of individuality and possibility, but does not notice doing so. Those disposed to power-over send a background message in every moment of interaction, "You will conform to my way of understanding and doing things because you have no choice; without me you can't handle your life." A usually unspoken conviction seals this message against critical awareness: "I have power over you because I am better than you. I am better than you because I don't need assistance with the same details in my life as you do."

The background message in power-over: "You will conform to my understanding of you because without me you can't handle your life."

Social expectations make power-over easy. Long-term need for assistance stimulates social fear that justifies separating people out as

devalued "others". The resources required to assist a person throughout their lifetime generates social resentment that justifies meanness of spirit and the imposition of control and stigma as a condition of assistance.

People with developmental disabilities act to shape and cope with impositions of power over them. They may actively withdraw into themselves, seeking invisibility by submerging the signs of their individuality in passivity or in intense effort to conform to expectations by being and saying what their assistants want. They may fight back by trying to frustrate or punish their controllers. They may seek to transform the people who impose on them by reaching out to befriend and heal them. Because others control so many of the details of their lives, a person's own activity can be easy to overlook –even to the extent of denying that the person acts to shape their world at all.

For a good discussion of difficult or withdrawn behavior as resistance to domination and the importance of power-with people, see Herb Lovett (1996). *Learning to listen: Positive approaches and difficult behavior.* Baltimore, MD: Paul Brookes. To study an agency that has struggled to understand power-with people, see John O'Brien, Connie Lyle O'Brien, and Gail Jacob (1998). *Celebrating the ordinary.* Toronto, ON: Inclusion Press.

Power-with

Power-with is a disposition to accompany people as they compose their lives. It is a willingness to be influenced by another's purposes and preferences and to negotiate agreements about how to help. Assistants striving for power-with those they help base their relationship on deep respect for the particulars that make a person who she uniquely is. They see the person's worth in the present and their potential for development in the future. They understand exclusion, rejection, and paternalistic or bureaucratic control as injustices that must be resisted so they will not take over a person's life.

This disposition seems to have more to do with what an assistant has learned from life than with what an assistant has read in school or heard from a supervisor. Some assistants say that it was just the way things were in their family or community life as they grew up. Others say that it results from their efforts to understand and heal the wounds of their own hard times. Relevant learning experiences and skilled supervision do help assistants develop their capacity for exercising power-with people, but it seems to be more a gift to be nurtured than a product to be demanded.

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Exercising power-with people means taking time to learn about a person's ideas of the sort of person they aspire to be, their current goals, and their sense of exactly what will be most helpful to them. It means handling the details in a way that has been negotiated. It means making time to discuss what is working and what needs to be improved. It means finding respectful ways to offer information, reactions, advice, and invitations to try new things.

The background messages as assistants help people hold the details of their lives are these: "Our respect for one another is worth protecting. Assisting you in a way that honors who you are and helps you move through your life in a positive way satisfies an important purpose in my life."

The background message in power-with: "Assisting you in a way that honors who you are and helps you move through your life in a positive way satisfies an important purpose in my life."

The details and overprotection

A common conflict occurs between people who have a good idea for improving a person's situation and those whose attention focuses on the day-to-day work of handling a person's details.

Those with a good idea –say assisting a person to take a job outside the shelter of a day activity program– often meet resistance from others close to the person. Their confidence in their good idea, which may well be justified, leads them to discount the concerns of those who live in the details because they think primarily about the benefits that the good idea will offer. Rather than puzzling over the disagreement and joining a search for a creative resolution to the conflict the disagreement introduces, people with good ideas about the future sometimes get frustrated and label those who disagree as overprotective. Frustration finds expression in the attribution of unpleasant motives for overprotection: "They just want to live off her benefits." "They have bad or backward values and want to hold him back."

People with a good idea think mostly about its benefits and get frustrated when people seem to get tangled-up in the details.

Those who live in the details of a vulnerable person's life, as most parents do for extended periods of their lives and as some direct service workers do if they stay with the work, have a visceral sense of the ways details lean on and link with each other. This can lead them to discount the benefits of changes because they think mostly about

People concerned about the details think mostly about a good idea's practical impact and get frustrated with abstractions.

the risk to the workable ways that the details get handled. Sometimes they sense that a positive change in one aspect of a person's life will negatively affect the management of details invisible to the people with a good idea for the future. Rather than puzzling over the potential in the good idea and joining a search for a creative resolution to the conflict the good idea introduces, people who live in the details sometimes become frustrated and label those with ideas about the future as unrealistic. Frustration finds expression in the attribution of unpleasant motives for good ideas: "They are social engineers experimenting on vulnerable people to promote some human service fad." "They are the agents of government cost cutters whose agenda is to deprive people with disabilities of the services they need."

People with developmental disabilities get caught in the middle.

People with developmental disabilities can get caught in the middle. When they count on and care about both the people who are inviting them into a good idea and the people who handle important details, they can choose one side over the other or they can signal the conflict by sending inconsistent messages. A person who expresses fears about loss of routine with those focused on the details and enthusiasm for possibilities with those encouraging a new idea communicates both their own uncertainty and their recognition that they don't want to alienate anyone that matters to them. The best way to loosen this bind is to search for a specific way to set the details in the context of possibilities opened by a good idea. This means listening to both the voice of the details and the voice of the good idea.

Our point is to highlight a common pattern in relationships that matter to people with disabilities rather than to judge particular circumstances. We have no difficulty imagining that sometimes people with good ideas can be in the grip of fads or troubling political agendas. We have no difficulty imagining that sometimes people who live in the details can be putting other concerns above what might be desirable and possible for a person, or even that some people may do so out of greed or willful backwardness. However, the pattern of dealing with conflict through mutual negative labeling and attribution of

distasteful motives makes it impossible to investigate any situation far enough to find out. The accuracy of the labels goes untested. Because these blaming statements can be the source of hurt and resentment when they are expressed aloud instead of kept quietly under the wraps of surface politeness, they generate a fear that trying to talk about the difference will only make things worse. This fear freezes the conflict into place: people with good ideas console one another by repeating stories about the overprotective to one another; people who live in the details console one another by repeating stories to one another about the unrealistic schemes they must defend against.

People fear that trying to talk through differences will just make things worse. When others stay stuck in their own point of view, they are right.

Such frozen conflicts have dire consequences. They interrupt a reasonable life-rhythm of enjoying stability and reaching out for new possibilities. They feed frustration because good ideas can't be implemented without the cooperation of those who hold the details, and those who hold the details feel the threat that those who can insist on pushing a good idea may pose to arrangements that work day-to-day. They divide people and reinforce poor habits for dealing with conflicts, thus fragmenting the support a person experiences and draining creative energy from a person's relationships. They stunt learning to improve the quality of life and the quality of services through such processes as person-centered planning.

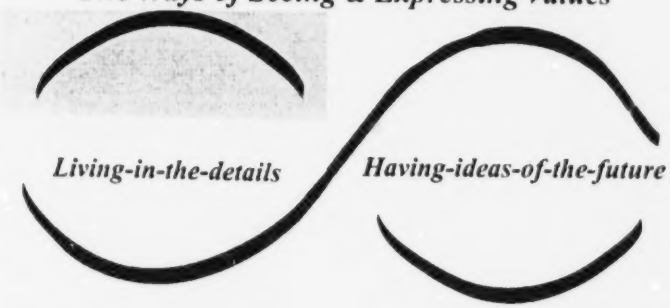
In contrasting people with good ideas about the future with people who live with the details we risk reproducing the problem we want to remedy. Discussion group participants got stuck in the overprotective-unrealistic pattern often enough to give us the confidence to highlight it. But it would be easy to read the discussion as if "people-who-live-in-the details" were a label that adequately described either parents or direct service workers. This would be false.

The parents of people with significant disabilities can and do act as "people-who-have-good-ideas". Many discussion participants have a history of making good things happen against bureaucratic and political inertia and the doubts of unimaginative service workers. Direct service workers can and do support people to create new possibilities.

But those who adequately handle the details for a person feel the pull of those details as their priority. When deprived of adequate resources or forced to invest significant energy in protecting access to the resources they count on, making dreams come true often gets deferred. One cruel result of Wisconsin's recent wave of denials of authorization for Medicaid card services to people with developmental disabilities who live with their families has been the compounding effect of taking away resources, decreasing confidence that resources will be available, and pulling energy away from making the best of the increasing number of ideas for better futures at just the moment when some managers want to reform their system by implementing self-directed services for people with developmental disabilities.

A better way to understand this difference contrasts two points of view, each of which reveals important dimensions of life with substantial disability. Each point of view is available to anyone willing to listen carefully enough to try it on. However, we think it will usually be easier for someone who has experienced living-in-the-details to inhabit the good-ideas-about-the-future perspective than it will be for someone without access to the experience of handling the details for another person over time to try on the living-in-the-details perspective.

Two Ways of Seeing & Expressing Values



Living-in-the-details	*Having-ideas-of-the-future*
present oriented	future oriented
more concrete	more conceptual
concern for "good enough" stability	concern for "closer to ideal" possibility
knowing ways things are tangled together	knowing one good thing
awareness of barriers & threats	awareness of direction

These two perspectives are purposely overdrawn to offer a tool for understanding. The question to ask to to use the tool is, "Could I look like this to people who don't seem to be understanding me."

When living-in-the-details, people feel the pull of immediate, concrete realities: who will assist

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the person to get dressed tomorrow or to survive next week's dental appointment. Stability in arrangements provides continuity which itself offers value as long as it results in assistance that seems good enough to keep the person secure and reasonably satisfied. While wanting the best for a person, people sometimes make compromises as they juggle multiple priorities and come face to face with barriers. New ideas raise practical questions, "Who, exactly, will do the work necessary to make this happen? How much of that work will fall to me to do? Exactly what practical help goes with this good idea?"

When having-ideas-about-the-future, people feel the pull of new possibilities, created first as ideas. Potential benefits of change outweigh concerns for stability. The desire to realize a best possible goal overshadows questions about details. The goal provides focus and direction and a search for specialized knowledge. Barriers increase the desire to "just do it."

Clearly, life will go better for a person whose allies practice considering what they value from both perspectives.

The details and the big idea of self-determination

Getting down to the details defines our point of view in this report. Because this is a time when service reformers struggle to grasp big ideas –like managed care and self-determination– this may seem like a perverse choice to those working with these big ideas. It may seem to them that adopting this point of view misses the promise of freedom or the overriding threat of impersonal cost controls and snares the wings of reform in a confusion of particulars. But, after we listened to the discussion groups, we chose to view the big idea of self-determination from underneath, exactly because of our commitment to increasing freedom. People who need to engage one another's perspectives seem too often to be frustrating one another by talking past each other.

People who need to engage each other's point of view too often talk past each other.

Those who live in the details –whether they are parents or service brokers or direct service workers– want to understand the impact of big ideas on the details. To them, talk about big ideas can seem to skate too fast onto thinning ice. For example, "This big idea seems

to count a lot on natural support. But some people have few relationships with others. Exactly who will be there for them, and where will these people get the time and skill to be of practical help?" They easily see the contradictions and uncertainties of a system in transition, and often the system's leaders seem to respond to their questions by repeating big ideas as if they were a reasonable answer to their concerns about the details.

System reformers want people to rise to a vision of new freedom and flexibility. What matters most to them is establishing a new administrative and social context in which people will deal with the details. Given the capacity to direct an individual budget and to bargain with service providers or organize their own supports with the assistance of an independent broker, people will grow by exercising a new responsibility to negotiate the supports that suit them. Those who respond to the vision with questions about details seem to be resisting necessary change and not getting the "it" of self-determination. "They are holding back change because they will not make the necessary paradigm shift."

Dealing responsibly with the differences calls on everyone involved to take a deep breath, suspend their immediate reactions, and try on another perspective.

Thoughtful conversation between people who live in the details and people with a vision that promises greater freedom will shape a better future. Dealing responsibly with the differences calls on everyone involved to take a deep breath, suspend their immediate reactions, and try on another perspective. The much repeated advice, "Seek to understand before seeking to be understood", fits here. But the prospect of losing something important makes following this good advice hard. Those worried about the loss of a stability good enough to hold most of the necessary details will need courage and self-discipline to accept an invitation to gamble on a new vision. Those worried about the loss of a chance to make a big improvement in people's opportunities will need courage and self-discipline to test their vision against the practical daily details.

These conversations become even more difficult when authority is unequal. A perception that those who raise detail questions are opponents tempts people in management positions to think of them-

selves as drivers of positive change who must heroically overcome resistance. A perception that those with the big idea are going to drive that idea through, regardless of its effects has two negative effects. It either discourages people into silence or stimulates them to mobilize countervailing power. It's easy to see the possibilities for escalating misunderstanding. It's hard to get unstuck from them.

Seeing the whole person

Wise choices about how to handle the details of a person's assistance and how to seek new possibilities depend on a shared appreciation of the whole person. While words can't pin down all there is to anyone, people with developmental disabilities will be better off if they and the people they count on think carefully together from time to time about their best answer to the question, "Who am I and what matters most in my life?"

Two common patterns limit the quality of people's answers to these key questions. The first pretends that the person can be understood singly, in isolation from relationships. The second leaves out important dimensions of the way the person experiences disability.

Seeing the person in relationship

Respecting the value of individuality can mask the fact that each person develops in relationship to others. The web of relationships that holds a person sometimes entangles the person in difficulties and conflicts. The web of relationships that holds a person sometimes energizes change. The web of relationships that holds a person sometimes provides the resources for bearing pain and loss. Members of the web of relationships can be close-by now or present in memory. They can be stingy or generous. They can be many and densely connected with each other or few and thinly spread.

Disability affects relationships, especially in the way life's details are handled. Parents's understanding of disability can lead them to seek legal guardianship of adults. The resources a system makes available may demand that people live with their parents much longer

and count on their parents for more intimate assistance than their brothers and sisters do. The social devaluation of people with disabilities draws parents to revisit the question, "What will happen to my child when I am gone?" Disability may also be one distinctive part of the pleasure and learning of raising a child and being a person's friend.

Whether a person struggles to be free of being held too tightly or yearns for more closeness, relationships matter. Whether people shrink from disapproval or flourish with encouragement, relationships matter. Whether people refuse a possibility for the sake of relationship or risk relationship for the sake of pursuing a possibility, relationships matter.

Being messy and confusing, relationships fit poorly into the kind of planning and management that efficient organizations are supposed to do.

Being often messy and confusing, relationships fit poorly into the kind of linear, rational planning that efficient organizations are supposed to do. This has led some agencies to discourage contact with anyone outside their control. When successful, this strategy reduces the person by shearing away important others. Sometimes the organizational rituals of individual program planning, service coordination and grievance processing work to tame relationships. But sometimes these containers overflow. When they do, things will go better for everyone if the people involved can find another way to process what troubles or excites them. An honest person-to-person conversation that leads people to step back and try another way to be with one another may move things forward. A third-party mediator may help. A different sort of planning or coordination method may work: some people report that gathering a circle to pursue a person-centered plan brought people into new and better relationships; others say engaging a service broker and directing an individual budget clarified roles in a satisfactory way. What will not work is hiding from the importance of relationships.

Perhaps in reaction to a history of ignoring the voices of people with developmental disabilities, some people committed to self-determination have adopted a relationship-free understanding of the self in self-determination. They believe that the only legitimate voice is the

person's own voice, perhaps amplified by a broker or advocate who acts only on the person's instructions.

Everyone can have difficult times finding a distance from others that leaves room for growth and supplies necessary support. Many people with developmental disabilities have been squeezed by so much control that they have difficulty finding their own voice. Many parents have had to put so much energy into the work of caring that they have too little room for their own thoughts and dreams. Many staff have embraced a system's regulations and controlled people's lives from behind a professional mask.

These relationship difficulties can't be dissolved in any magic potion. Inflating any single voice –whether the person's, the parent's, or staff's – to the point of monologue only makes things worse. It will help to recognize one another as distinct people with unique gifts, responsibilities, and limitations; people whose voices merit respectful attention and whose claims on assistance deserve a generous response. It will help to make extra effort to amplify voices silenced by a history of being controlled and ignored. It will help to consider at least four dimensions of disability.

Relationship difficulties can't be dissolved in any magic potion.

A rhythm for decision making

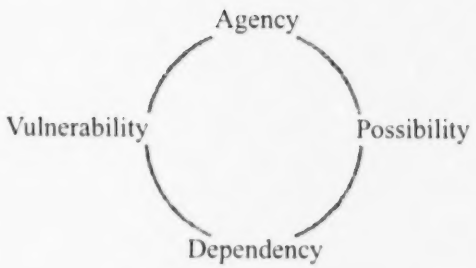
As we listened to discussion group participants, we began to hear a sort of rhythm in people's contributions. Participants, whether staff or parents, would talk for a time about people with developmental disabilities taking more control over their own lives – by directing an individual budget and hiring their own staff for example. Then the discussion would shift toward the limits on people's ability to choose. Participants would talk for a time about a possibility that excites them, home ownership for example. Then the discussion would shift toward the risks that possibility introduces into people's lives.

This rhythm seems to us to express a kind of wisdom. Not too far into being in charge without considering necessary support. Not too far into new opportunities without taking account of risks. Not too far into discussion of dangers without reaching out for information

about new possibilities. Not too far into talking about needs for services before talking about a person's identity and goals. It suggests that a thoughtful conversation about developmental disability will incorporate two pairs of opposing realities.

- People with developmental disabilities have **agency**, the capacity to set goals and take action toward them, **and** they experience **dependency**, a person-specific need for accommodation, adaptation, and assistance without which the person's disability and other's reactions to the person's disability will block action toward goals that matter to the person.
- The growth of new forms of assistance and changing social expectations offer people with developmental disabilities new **possibility**, **and** they experience **vulnerability** to impoverishment, rejection, isolation, neglect, and abuse because, despite progress, they remain in a devalued social status.

These two pairs of opposites suggest a pattern for thoughtful conversation. Good decisions call for good information. Good decisions also pull together what's learned by looking at that information from each of the four positions on this **decision circle**.



This integration of judgements around the circle challenges two habits: 1) thinking like a light switch; and 2) pushing away information that threatens comfortable ways to understand.

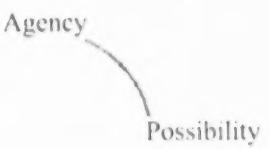
Beyond light-switch thinking

For many people, discussions seem clearer when things can be assigned a definite position: yes or no, right or wrong, he can or he can't. Conclusions that are like light switches, either on or off, seem easier to handle than conclusions that contain opposites: with the right support she can. The decision circle says that a person experiences both agency and dependence; both possibility and vulnerability. The keys to difficulties in one position may be found in the other three positions.

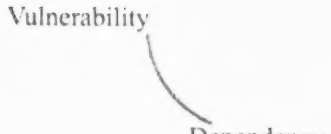
For a long time, professionals applied light-switch thinking, and some professionals still do. They judged people educable or ineducable, appropriate for work placement or infeasible for rehabilitation, skilled enough to live in their own home or incapable of doing so. These judgements became self-fulfilling prophecies when parents and people with disabilities accepted both the conclusion (she can not learn to communicate) and the light-switch way of thinking (there are only two boxes and she either fits in one or the other). The inventors of new possibilities, who were often parents, rejected light-switch thinking and asked a question that calls for a different kind of thinking, "What could we try that would improve her chances of communicating?"

In decision circle thinking, dependency becomes a reality to challenge with possibility. A person who communicates very little is no less valuable or whole than a person who eloquently uses his Liberator (a communication device) to make his thoughts known. But the person who communicates more easily usually has greater scope for agency, and so it is worth testing different ways of handling the details around dependency.

Beyond comfortable angles of view



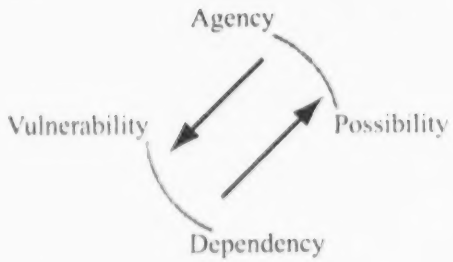
People seem to have comfortable, or at least habitual, positions on the decision circle. Some people thrive on discussions of agency and possibility. This preference can arise from a sense of the injustice that has been visited on people with developmental disabilities, many of whom were extracted from their families and communities and segregated in facilities that mindlessly controlled the details of their lives, from bedtime to what could be eaten for a snack. It can arise from awareness of the extent to which new technologies make it possible for people with disabilities to break out of low expectations into new kinds of satisfactions. It can arise from delight at the positive ways that people change when they have opportunities and supports that suit them.



Some people are profoundly aware of vulnerability and dependency. This may arise from direct experience of rejection, neglect, or abuse or from fighting systems that beat down efforts to pursue goals beyond that system's current horizon. It may arise from a sense of shame attached to disability. It may arise from a sober reading of the signs of the times: people too rushed to make time for others who need accommodation; difficult news about the heightened incidence of bullying, exploitation, and sexual abuse among people with developmental disabilities; and continuing legislative definition of the work of assisting people with disabilities as worth less in pay and benefits than assembling tacos.

Though it may seem odd to call a focus on dependency and vulnerability a comfortable point of view, it can become comfortable at least in that it offers predictability. "He is not capable of working, period," defines a reality to adapt to. "We can probably find an employer who will make the necessary accommodations for him to work," opens a possibility and increases uncertainty. And not just uncertainty about the future, but a kind of uncertainty about the past as well. "If he succeeds at work, then what does that say about our past judgements of his ability?"

Whether our discussions were with staff or with parents, we found a few people who could look from each pole of the decision circle, some people who seemed most comfortable looking at the world from the point of view of dependency and vulnerability, and other people who seemed most comfortable emphasizing agency and possibility. In both parent and staff groups, people reported painful and angering experiences of failed understanding. Parents who see possibilities talked about fruitless collisions with staff who only wanted to talk about their son or daughter's dependency in rigid terms. Staff who hear reasonable expressions of positive desire from people they know and care about talked of guardians who refuse to think about moving beyond restrictive living or day service arrangements.



There seem to be two ways to stay in a comfortable position. Either simply avoid listening to anyone who looks at things from the other half of the decision circle or polarize discussions by reacting against voices from the other half of the decision circle. Protecting a comfortable angle of view by dismissing people as "backward and overprotective" or "dangerously unrealistic" will polarize discussion, even if these dismissive judgements are never spoken aloud. So will finding differences that silence the other perspective: "That's all very nice for her, but the person I'm concerned about is very different and it could never work for her." or "Parents have to learn to 'let go'."

Often, people find ways to avoid conflict by retreating. One avenue of retreat holds that "The parents are always right, whether we personally agree with them or not." Another says, "One size can't fit all. We need to offer a full continuum of services and place people in the setting professionals choose or the setting parents want." These retreats might avoid hurt feelings, but they have costs.

Over-focus on vulnerability and dependency can leave people stuck. Over-focus on possibility and agency can leave people in danger.

Staying inside either half-circle creates fewer opportunities than considering the whole decision circle does. Over-focus on vulnerability and dependency can leave people stuck in settings that restrict their development and control them into helplessness. Over-focus on possibility and agency can leave people vulnerable without thoughtful assistance or adequate safeguards.

Learning to move around the whole decision circle can stimulate creativity. For example, some parent and staff participants see strengthening a person's own sense of voice and agency as a vital safeguard against abuse and neglect. People who know their rights have a better chance of reaching out to others when they are neglected or abused than people who live silently in helplessness.

If people with developmental disabilities and the people who handle the details of their lives can move beyond comfortable ways of making sense of their world, they may find a rhythm of conversation

that leads to greater opportunity and security. This rhythm paces movement around the decision circle, incorporating familiar views and uncomfortable views into clear decisions about how people will live and grow together.

Deciding how much to invest in relationships

Good relationships take hard work and time. Whether the way to a productive relationship seems to lead through better handling difficult emotions, or finding a balance between handling the details and pursuing good ideas for the future, or conversing around the decision circle, each person involved will have to see the benefit in building a stronger relationship.

A spectrum of relationship strategies

In our discussions, we heard about a spectrum of strategies for dealing with relationships.

From staff we heard...

MINIMIZE

... avoid parents by focusing attention on people who have no active family contact

... have as little to do with parents as possible: don't tell, don't ask about difficulties and give them regular good news

... if parents insist, either tell them whatever they want to hear and then go ahead and do what you know is right, or do whatever they say regardless of whether you think it is right or not

FORMALIZE

... keep things formal: draw clear boundaries between staff and parent roles, stay inside job descriptions, stick to policy and procedure, make plans through the agency's routine, if parents have problems encourage them to use the grievance procedure

PERSONALIZE

... make time to get to know each other as people, learn something about the parent's story, figure out ways to collaborate on something that the person will benefit from, find ways to talk honestly when problems come up

From parents we heard...

... it's easier to do it myself than to deal with agency and staff and the system, our son or daughter stays home with me — MINIMIZE

... letting go is hard but necessary, we trust the agency to do the right thing and we do not interfere with professional judgements, we have limited contact with our son or daughter

... we attend planning meetings and monitor what goes on; if we notice a problem, we call the supervisor or the agency director or the county — FORMALIZE

... we are using an individual budget to choose the agency that gets our business and we will take our business elsewhere if they can't satisfy us

... we take an active role in the agency's hiring process — CONTROL

... we (often in collaboration with other families) are using an individual budget to self-manage the services our son or daughter receives; the staff work for us (though they may be paid through a fiscal intermediary or co-employed with an agency that acts as employer of record)

... whether we hire or supervise them or not, we take time to get to know at least the key staff people in our son or daughter's life, we try to learn something about their story, we try to find ways to talk honestly when problems come up, if we can we encourage them in their own lives — PERSONALIZE

Each of these strategies fit the circumstances of the people who use them, but those that minimize or formalize relationships reduce the chances that staff and parents will be able to fully use differences in perspective and resources to increase a person's security and opportunity. This does not necessarily mean that a person will be insecure or lack for opportunities. What would be missed is what might come from collaboration between parents and staff.

Strategies might mis-match. Staff who want to personalize their relationship might react to parents who want to keep things formal as distant and authoritarian. Parents who want to minimize their

investment in staff might feel uncomfortable with staff who see active participation in agency activities as a sign of interest.

The context of available services makes a powerful difference to which strategy makes sense. Those living in a place that offers individualized supports and has invested in making support work meaningful and worthwhile to staff have far more freedom to choose their distance from each other than those whose only service options manage groups of people under the supervision of low-paid, high turn-over staff.

Transaction or investment?

Spending scarce time and energy on staff people can seem like an unfair drain on families

The idea of parents taking an active interest in staff seems peculiar to many people. They see assistance as a straightforward business transaction. Being cordial makes sense, and it could be good business for staff people to take a non-intrusive interest in the family, but spending scarce time and energy on learning about and encouraging staff people seems like an unfair drain on families that have already worked hard enough to assist their sons and daughters. The strategy of investment blurs boundaries that should be kept clear.

Thinking of the parent-staff relationship as a transaction captures an important reality. Staff get paid to provide the assistance that people need. They have a job, and with that job a set of obligations and protections. Many social trends support seeing staff's work as a straightforward transaction: a growing consumerism that has strongly influenced ideas about self-determination for people with developmental disabilities; a concern with efficiency and outcomes; and a value on convenience and minimizing the money and time costs of getting results; and the great demand for spending time in paid work.

Those parents who choose a personalized relationship with staff believe and see that different things become possible when the relationship is more than a transaction. It is important to know that these parents's sons and daughters have substantial disabilities and have received moderate to high levels of support as young people. As one parent describes herself, "I'm not as tired as mothers who have done

most of the work for decades." They have chosen an active role in defining and guiding their son's and daughter's assistance and living arrangements.

These parents see investment in relationship building as one part of maintaining continuity by keeping trustworthy and able staff at work. Staff who have the time to develop knowledge of the person they support have a greater potential to contribute to the person's life quality. Parents who invest see staff as needing time and guidance to understand communication impairments or health conditions or behavioral difficulties. They see committed staff do more than simply watch the person and call for help if things get out of hand and they value the ways in which committed staff contribute to the quality of their son or daughter's life. They see that staff who have taken major roles in a person's life can sometimes shift into minor roles or back up work because committed staff value the person they have come to know. Moreover, as long as the current scarcity of workers continues, investing time in relationship building can reduce time spent recruiting and patching up schedules. Commitment is valuable, and parents who invest know that they can nurture staff commitment.

Formal systems of accountability can't substitute for trust.

Formal systems of accountability can't substitute for trust. Holding life details for a person who needs substantial assistance can be very demanding whether done by parents or done by paid staff. It is almost inevitable that sometimes an important detail will drop. Cover-ups always make errors worse and it takes time and trust for staff to risk reporting fully, quickly, and honestly.

In times of sickness or emotional difficulty, stress can lead to heightened emotions and errors. When there has been a chance to get to know the staff person, evaluations are easier than when the staff person is nearly a stranger. It is also easier for a staff person to reciprocate an attitude of forgiveness and generosity when a parent reaches the end of her rope than it is to offer what has never been received.

Many qualities that enrich a person's life can't be found by simply following a job description.

Many qualities that enrich a person's life can't be found by simply following a job description or a schedule. It's one thing to go on a walk with someone who is just following orders, another to go for a scheduled walk with someone who is interested in what you notice and what you might enjoy. Parental investment in helping a staff member build a story of who the person is can help staff discover how to add their particular contribution to that story.

Parents are not the sole or necessary source of investment in staff. People with developmental disabilities themselves often make irreplaceable investments in their relationships with the people who assist them, as long as their staff are open to them. Effective supervisors and leaders in agencies can make the same sort of investments that parents can. But some parents's experience makes it clear that there can be far more to high quality self-managed or family-managed services than issuing orders to employees.

Back to our question

Through listening to many discussions, we learned how hard it is to create relationships that make productive use of differences to increase security and opportunity for people with developmental disabilities.

Our respect grew for the courage of those parents and staff who have found ways to try on a different point of view before pushing their own authoritative answer. We learned that this is harder than the advice about good communication makes it sound.

Our appreciation grew for those times when parents and staff achieve any measure of shared understanding, find an effective way to collaborate on any jointly meaningful objective, negotiate a creative resolution for any conflict, or reconcile when stress and a too rapid pace of life leads to broken promises. We learned that these moments are less frequent and less far reaching than we would have thought.

Our wonder grew at the resilience of people with developmental disabilities, so many of whom get on with the task of reshaping an inhospitable world regardless of the difficulties that the people they count on may have in relating to one another.

Through the time we spent listening, the ideal of bringing together different ways of understanding the life of a person with a disability grew more and more precious.